



## Partners in Living E-learning Course

### Assignment: Learning from Others' Success Mary's Story

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### Mary's Story

*by Jan Lampman, Executive Director of The ARC of Midland, Michigan.*

Mary's dream is to simply live her life. She doesn't want to be rich or famous. She doesn't want to go to the moon or even anywhere farther away than sunny Florida. She wants to have a nice place to live; she wants to spend time with family and friends, she wants to make a little money so that she can buy new purses and she wants to help kids who don't have enough money for warm winter clothes. Oh and she wants to do those things on her own terms.

Mary has a very ordinary life, but has taken an extraordinary road to get that life. Mary was born in 1953. We don't know where she was born, but she was raised by Bobbi Wheeler in Saginaw, Michigan. Mary was born with cerebral palsy, which caused spastic quadriplegia and mental retardation. Mary never walked. She did learn to crawl, however. She did not go to school, but went everywhere with Bobbi. She did not have a wheelchair, so Bobbi carried her everywhere. Mary saw a lot in her first 12 years of life with Bobbi. The Wheelers lived in a rough neighborhood. Mary saw her two brothers and sister go to jail many times. She even saw her mother, Bobbi, shot by a former boyfriend.

At the age of twelve, Mary was placed in the Mt. Pleasant Regional Center. This is when, according to Mary, life got bad. Mary lived at the Center for 15 years. During her years at the Center, up to 2000 other people with disabilities lived at the institution. Mary cannot think of a single positive story from the institution. She did get a wheelchair, but was left to sit in the chair for hours on end. She was even allowed to roll down a hill and fell out of the chair one time. She broke a tooth on that day.

Although Mary never walked, she did crawl everywhere she wanted to go within her home. She was proud of her ability to get into and out of bed, get to the bathroom and turn on her TV. That all ended while she was living at the institution. Sometime during the late 1960's Mary had several surgeries to fuse her ankles, knees and hips. These surgeries robbed Mary of her ability to transfer into and out of bed and to crawl. Of course, no one asked Mary if she wanted these procedures. In addition to causing Mary a loss of independence, the procedures had the unintended consequence of causing Mary to develop a near phobic reaction to any medical procedure.

Besides losing her ability to move on her own, Mary also lost her family to the institution. In the 1960's family members were told to limit visits and "separate" from the family member living in the institution. Mary only saw her mother once or twice each year until Bobbi died in 1986. She lost track of her siblings for several years.

Mary finally moved from the institution to a 6-bed group home in 1980. Mary will tell you that life did not get any better. There were fewer people, but they were mostly people that Mary did not

like. She did not enjoy the same activities. She did not watch the same TV shows. She did not like the same kind of food. That did not matter, however. Mary did go on the group outings. She did have to eat the same foods at the same time as the housemates who she would have rather never had to see or hear.

Mary did not choose what to eat, where she would go each day, who she would go with, who would help her into and out of bed. Mary rarely saw any family members and she had no friends. Many of the staff people were nice, but many were not and Mary had no input into who was hired to provide her care.

When Mary tried to rebel, she was labeled "behaviorally challenged" and put on behavioral treatment programs. Mary's life began to change when she met Mark Lampman. The husband of one of Mary's direct support staff (me), Mark became Mary's biggest ally.

In the past 18 years, Mary and Mark have worked to move steadfastly toward the ordinary life that Mary has always desired. First, Mary moved into a two-bed group home. She still did not choose whom she would live with, however. There was an assumption that since she was African American, that she would surely want to live with another person who is African American. Mary hated her housemate. She wanted to choose her housemate.

The home was a licensed facility, so the rules about 24 hour staff, occupational therapy and audits were still a part of Mary's life. She still ate what someone else chose, worked on therapy goals that others determined and followed rules made by government regulators. While living at the 2-bed group home, Mary had three therapists, 24 hour staffing, and a psychologist because she was still considered a behavior problem and a housemate that drove her crazy. She also spent five days per week at a workshop earning about \$7 per week. None of these things were what Mary chose.

Mary often spent weekends at our house. At one point, Mark was advocating with Mary concerning a recipient rights dispute with the local group home provider. Mary actually lived with us for a month. This is when Mary started to think and dream of a life without "the system."

When she stayed with us, she got to stay alone sometimes. She got to eat what she wanted, when she wanted. She got a TV of her own and got to learn to use the remote to select the channels. She also learned to use a cordless phone. In one month, Mary learned the remote, the cordless phone, how to communicate with Mark's secretary (Mary's speech is difficult to understand due to the CP) and how to take her own medications. In one month, Mary accomplished more than years of therapy in the institution and group home. She also decided that she wanted to live in her own home, so that she could decide everything for herself.

In 1991 Mary finally got her chance to move into her own home. At first she had a case manager, who decided many things, such as how much staffing would be available to Mary. Mary decided, however, whom she would live with. She decided what to eat, when to eat, when to go to bed, when to get up, what to wear and when and where to go in the community. Mary learned to use public transportation. She learned to tell time. She learned to turn her VCR on with a baton.

There were still struggles. Mary did not like having 16 hours per day of staff. She found that she did not like having a housemate, even a person without disabilities. She felt that staff and her case manager did not really listen to her needs. They always said "we have to ask Mark about

that.” She also wanted to make some money. Sometimes Mary figured out how to get what she wanted and sometimes Mark intervened.

One occasion when Mark intervened was when the sheltered workshop was asked to help Mary find a job in the community. The assistant director of the workshop told Mark that his expectation that Mary would get a minimum wage job in the community was unrealistic. Mark simply said, “OK, thank you for your time.” He went to his office and made some phone calls and by the end of the day, he had found three jobs for Mary. She got to choose! She worked successfully at the job that she selected until diabetes and complications of the disease prevented her from working outside of her home.

Unfortunately, this happened before the Self-Determination “movement,” so Mary was unable to redirect the dollars that had been going to the workshop. She did not need them anyway. As it turned out, her coworkers provided her needed job supports, and her home staff went to her workplace to help with any personal care needs when they came up.

One occasion when Mary intervened to get what she needed to have done was when I took her to purchase some new furniture for her home. She needed a new couch and a chair. Mary had been complaining that she did not really need so many hours of staff around. Her case manager and I were still worried about her being home alone.

As we walked through the furniture store, Mary selected a small wooden bench and a small wooden chair for her living room. I explained to her that these pieces were not really very good because they would be uncomfortable. She said that she wanted uncomfortable furniture so that the staff would not just sit around. She pointed out that there is not enough work for them to do, so they just sit around getting paid to sleep or do their homework!

That was when I told Mary and Mark that I would join them in their quest for fewer staff. Now, Mary decides when staff work. She has only about 7 hours per day of paid staffing. Staff come in when needed and leave when they are done. Mary calls for help if she needs something.

Mary was one of the first in our community to get control of her entire budget. When that happened, she hired her own staff instead of using a provider. She hired an independent support coordinator. She pays a staff person extra to carry a cell phone for 24-hour emergency backup. She hired a “cute young guy” to exercise with her. She does not spend her support budget on anything, except what she really needs. She tries to find non-system ways to get her needs met. She has developed a safe and effective support structure for a fraction of the cost of her old group homes or institution. She is happier. Her staff is happier. In fact, there has been virtually no turnover since Mary started hiring her own staff in 1997. (Turnover had always been one of Mary’s chief complaints about the provider agencies).

Mary has many friends. She has reconnected with her family. She has a team of staff who works for her, and is loyal only to her and her needs. She has learned many skills that are necessary when you live a real life in the community. She had a job, but now she has a small home based business as a personal shopper (she loves to shop), and helping people price items for garage sales.

Mary’s health has even improved – less stress, lower blood pressure and better blood sugar. She also has helped “the system” to learn about what can be gained when you give people a chance to control their own lives and the resources needed to support those lives.

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She is no longer considered a behavior problem. Rather, she is known for her sense of hospitality and the great parties that she throws. She is known for her purses and her hats. She is known for the great hats that she makes for charity. She is known as a great boss. She is known to be a shrewd negotiator. She is known for her ability to find a good deal. She is also known as a great teacher.

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